

**Lyme Disease Advisory Committee
Minutes of the March 14, 2002 Meeting
Department of Health Services, Sacramento**

The sixth meeting of the Lyme Disease Advisory Committee (LDAC) was held on March 14, 2002, in Sacramento, California.

Committee members

Vicki Kramer, Ph.D., California Department of Health Services
Robert Lane, Ph.D., University of California, Berkeley
Lee Lull, Lyme Disease Support Network
Scott Morrow, M.D., California Conference of Local Health Officers
Susie Merrill, Lyme Disease Support Network
James Miller, Ph.D., University of California, Los Angeles
Christian Parlier, Lyme Disease Support Network
Raphael Stricker, M.D., California Medical Association

Other attendees

Anne Kjemtrup, D.V.M., Ph.D., California Department of Health Services
Peter Mackler, California Department of Health Services
Approximately 35 people representing the interested public and public agencies

I. Opening comments

The meeting was brought to order at 10:06. Dr. James Miller was introduced as a new member of the LDAC, filling the second academic position on the Committee. It was also announced that Ms. Jean Hubbard is no longer a member of the Committee. Her hard work and dedication to the Committee were acknowledged.

II. Review minutes of 11/28/01 meeting

Minutes of the November 28, 2001 meeting were reviewed by the Committee and approved via email on February 13, 2002. Minutes will be posted on the Department of Health Services' (DHS) web site.
(<http://www.dhs.cahwnet.gov/ps/dcdc/disb/disbindex.htm>)

III. DHS progress report

Dr. Kjemtrup presented a progress report on DHS tick-borne disease education and prevention activities since the last LDAC meeting in November 2001.

Education of the Medical Community. A presentation to physicians of the Alta Bates Summit Medical Center in Berkeley was given in January. The editor of the "The Action Report", the quarterly publication of the Medical Board of California, was contacted

regarding a follow-up article on Lyme disease. Permission was received to submit a two-paragraph article with three references for the July edition. Several physician associations were contacted to inquire about incorporating a tick-borne disease colloquium within already established conferences.

Education of the General Public. A press release on winter adult tick activity was issued in December. This generated one interview with a radio station in Los Angeles. The *Ixodes pacificus* distribution map being developed for the Internet has been improved. Users will now be able to click on a county on the state map and jump directly to the data pertinent for that county. This map and database should be posted on the web shortly. Modifications of the public information brochure were outlined.

Education of Public Agencies. Two presentations were made at the Mosquito and Vector Control Association of California annual conference on tick-borne disease surveillance methods and the DHS Lyme disease (LD) education program. Public health agencies that test ticks for individuals were contacted and requested to share data with DHS for incorporation into a new database. These agencies were also reminded that the press should be notified about tick-borne diseases during peak tick season or if the agency has new surveillance information.

In reference to presentations given on LD by DHS, it was requested that DHS notify the LDAC of upcoming presentations via email when possible.

Surveillance activities included tick collection in 22 locations in 12 counties. Ticks were collected and tested for *B. burgdorferi* from 14 of these sites.

Questions from the Committee clarified that 1) the tick testing methods are not all the same and have varying degrees of accuracy (some labs use fluorescent antibody tests, whereas others use the polymerase chain reaction), 2) attempts will be made to incorporate tick collection/testing data from other agencies and studies into the statewide database, and 3) sampling sites for tick surveillance are based primarily on identifying prime tick habitat where human exposure is a possibility. It was suggested that a statement be made on the map that the data presented do not represent all counties in the state.

IV. Discussion of DHS Lyme Disease Brochure

The LD public information brochure has gone through several versions and many of the Committee's suggestions have been incorporated into the current version. This meeting provided an opportunity for the Committee to fine-tune the language and layout of the brochure. The Committee discussed each section of the brochure.

Suggestions relative to the front cover included wording on tick distribution throughout California and inclusion of a statement that the map is based on data collected "to date" A date would also be included on the back cover of the brochure. In the symptom section, it was suggested that neuropsychiatric symptoms in children should be

included. It was also suggested that the diagnostic value of the EM rash should be emphasized. Because space is limited in the brochure, it was suggested that additional symptoms of LD could be listed on the DHS web site. Other suggestions regarding symptoms included emphasizing that LD is difficult to diagnosis and treat, that LD is a clinical diagnosis, and that much needs to be learned about this complex disease. Regarding the erythema migrans (EM) rashes, it was suggested that additional examples of rashes other than “bulls-eye” rashes should be included.

In the transmission section, grammatical clarifications were suggested. The Committee discussed the best way to present information on *B. burgdorferi* infection rates in ticks. Suggestions included presenting a range of infectivity, an average, or stating “up to” in order to emphasize that LD is a real problem in California. It was stressed that the risk of nymphal ticks transmitting the disease to humans be emphasized.

Suggestions for the prevention section included adding DEET as a repellent, verifying that the “actual size” photo is indeed actual size, and noting that on some of the tick pictures, the photos have been enlarged to show detail.

Suggestions on the LD and other tick-borne disease section included grammatical corrections and including the names of other tick-borne diseases.

V. Physician education

Dr. Kjemtrup presented the proposed education program targeting physicians and outlined the main issues to address with this program. These issues include: 1) how to disseminate information to California physicians, 2) the media that would be most effective in conveying information (e.g. newsletter, tick i.d. cards, etc) and 3) how to assess the effectiveness of the program. To address these issues, a draft Physician Questionnaire has been developed. It could be sent to a sample of physicians in California, and then an education program targeting half of these physicians could be implemented. A follow-up questionnaire would finally be developed and distributed to evaluate program effectiveness.

Committee members were asked to review the draft questionnaire. Sampling methods were deemed to be important for validity of results. The best means to contact physicians and encourage a high response rate was discussed. Suggestions included offering an incentive (e.g. educational materials) in return for filling out the form. Follow-up telephone contact would likely increase the response level. A telephone survey instead of a mail survey was also suggested as a method to assess physician knowledge. Specific suggestions on the questionnaire included grammatical corrections, removal of the question regarding the vaccine, and inclusion of more questions on symptoms. These suggestions will be considered for the next meeting when a plan for physician assessment will be presented. LDAC members were encouraged to contact Dr. Kjemtrup with specific suggestions on the questionnaire within the next month.

At the suggestion of the LDAC, the possibility of presenting a seminar on LD in California as a means to educate physicians was investigated. DHS recommended that linking up with a pre-existing conference was the most efficient approach to implementing such a colloquium. . DHS agreed that a balance of opinion on clinical aspects, including a physician who is routinely treating LD patients, be incorporated into any program, and that other aspects such as epidemiology, case occurrence, entomology, and clinical presentations could be also be included. The Committee was asked to suggest organizations that would be amenable to including such a seminar.

Another tool for physician education includes the two paragraph follow-up article to be submitted for publication in the Action Alert newsletter, the Medical Board's quarterly newsletter sent to over 60,000 physicians in California. DHS suggested that the two paragraphs focus on 1) the Center for Disease Control and Prevention's (CDC) announcement earlier this year about the increase in LD cases nationwide and 2) the removal of the LD vaccine from the market. At the November 2001 meeting, Committee members had been asked to propose scientific references that would provide information and points of view regarding diagnosis and treatment that were not expressed by the references cited in the first article. It was suggested that review articles might be the most useful. In addition to articles already proposed, the Committee was asked to propose some review articles for further consideration. From these suggested references, DHS would then send to the Committee a list of about five references to consider. The committee agreed that other tick-borne disease issues, although important, might be better used as an opportunity for even more articles in the future. Since one of the paragraphs will focus on the increase in Lyme disease cases nationwide, the January 2002 Morbidity and Mortality Weekly Report (MMWR) released by the Centers for Disease Control and Prevention, which described recent epidemiological trends in LD, would be one of the references.

VI. Public comment

Ms. Patricia Smith from New Jersey, President of the Lyme Disease Association (LDA), spoke first. She explained that the LDA funds research on LD, including an ongoing project at the University of California, Davis. The LDA has 5 affiliates in California. She noted that opinions have changed about LD and that we can no longer bury our heads in the sand because of the many, many sick people. She described the extensive *Borrelia* tick-testing program that she witnessed at the United States Army Center for Health Promotion and Preventive Medicine (CHPPM) and noted that with such an extensive program it is obvious that there is great concern about the consequences of this disease. She noted that the neuropsychiatric issues of this disease really need to be emphasized and that kids are out of school for many years due to LD infection. She said that because of the persistence of the infection, there is no evidence that 28 days of antibiotics cures the infection. She stated that LD patients are taking matters into their own hands through legislative hearings on LD. She made some suggestions pertinent to the DHS brochure and added that she would like to see a dual reporting system where cases that meet the CDC case definition and those that don't are tracked. She emphasized that LD is a clinical diagnosis. She suggested that DHS offer 0.5 CME

credit to physicians for filling in the questionnaire. She offered help to set up physician seminars and described the International Lyme and Associated Diseases Society (ILADS) organization as a group of health professionals who provide information on LD.

Dr. Therese Yang spoke next. She is a family practitioner from San Diego and works at a nonprofit clinic as a full-time volunteer trying to help LD patients. She noted that physicians need education on treatment options. But to do this, one needs to catch their attention and prove that a problem is here. She noted that long-term antibiotics do cause problems but not treating LD patients causes more harm and is negligent. She stated that we need to break through the insurance wall and help the physicians help LD patients.

Ms. Myrna Vallejo spoke next. She tried to go off antibiotics in the summer and could barely walk. Now she is back on antibiotics and is much better. She stated that she is living proof that LD is not easily cured but instead has made victims of persons with chronic LD. She stated that DHS should take care of people, not take sides.

The following speaker was John Ott from Orange County. As a business trial attorney he has represented physicians in malpractice suits. His wife has had LD since October 1996. He had to spend \$30,000 to go through tests to prove what they knew was true. He learned that doctors around the country were being persecuted for treating LD patients. He had to fight insurance companies for treatment for his wife. Many of the doctors know that there is no answer to many of these issues and it is immoral to tell doctors how to treat the disease. Making a universal standard is impossible. Yesterday they learned that their 6-year-old boy also has LD and were told that the boy acquired the infection from the boy's mother.

Marlene Hauk from the Butte County Lyme Disease Support group spoke next. She stated that there are many cases of LD in Butte County. She is aware of 2 recent LD related deaths. In the first case, a woman infected with LD committed suicide in January because she felt she would be a burden to society. The second person was told by UC Davis Medical Center that he did not have LD; he was taken off antibiotics and put on steroids. The person declined rapidly and died March 3rd. She stated that this is the 4th LD related death in her area. She suggested that the physician education program needs to emphasize that LD kills people. Physicians need to be able to recognize EM rashes and know that short-term antibiotic treatment will not get rid of LD. She stated that the physician education program determined by the Committee will determine the education of the medical world on LD and this will affect the future treatment of LD.

Ms. Lilly Grewald spoke next. As a high school student suffering from LD, she stated that schools need to be informed about LD, particularly in southern California where her family was told that there is no LD. Her disease has impacted her schoolwork tremendously and her family had to hire lawyers. She displayed a photomicrograph of her bone marrow smear and stated that the smear was evidence that she was also coinfecting with *Babesia*.

Ms. Terry Mitchell-Charonet spoke next. She thanked the Committee and noted that we have a big job ahead of us. She helped diagnose herself through DHS' old brochure because of the map that said LD is present in California. Every physician in the community needs to know about LD. She stated that she works at children's hospitals and that agencies such as elementary schools and forest ranger programs need to be informed about LD. She suggested that the brochure needs to be printed in large quantities for wide distribution.

Dr. Lynn Shepler spoke next. She thanked Ms. Smith and Ms Hubbard. She felt we are not working together and stated that it is outrageous that people with no medical training are running the Committee. She felt that the way meetings are run needs to change and that DHS should not force policy on human clinical medicine.

The meeting was adjourned at 3:30 p.m.